

FINDINGS OF THE 2001 PUBLIC FORUMS ON DEVELOPMENTAL DISABILITIES SERVICES



Sponsored by

The Developmental Disabilities Planning
and Advisory Council

And

The Montana Advocacy Program

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INTRODUCTION

During the fall of 2001 the Developmental Disabilities Planning and Advisory Council, in partnership with the Montana Advocacy Program, embarked on a series of six public forums across Montana to seek public input on developmental disabilities services.

In addition to the six public forums, the Council and Advocacy Program jointly sponsored a METNET Stakeholders Priority Sharing Opportunity utilizing all satellite downlink capabilities in the state.

The Council independently disseminated 3,700 written survey tools statewide seeking self-advocate, parent-advocate and professionals priorities and proposed plans-of-action, to implement those priorities.

This report contains the findings of these three strategies to gather input from Montanan's on developmental disabilities services.

WHO WILL USE THESE RESULTS

These results will be used by the Developmental Disabilities Planning and Advisory Council to assist the Council in developing our priorities for issues to address with Council resources;

The Montana Advocacy Program will use these results to assist in refining goals and activities;

and,

The Disability Services Division of the Department of Public Health and Human Services will use these results to assist in defining potential legislative recommendations before the 2003 Montana State Legislature.

Persons who attended a public forum and listed their name and address and persons completing the survey tool and included their name and address will receive a copy of the report.

The report will also be disseminated to all stakeholders in the developmental disabilities service system, members of the Montana State Legislature, members of the Montana Congressional Delegation, the Governor's Office and the Director of the Department of Public Health & Human Services.

PUBLIC FORUM LOCATIONS AND ATTENDANCE

State Region	Date	Town	Attendance
One	Oct. 18	Miles City	24
Two	Oct. 17	Great Falls	10
Three	Oct. 23	Lewistown/evening	4
Three	Oct. 23	Lewistown/afternoon	16
Three	Oct. 4	Billings	135
Four	Oct. 22	Butte	9
Five	Oct. 16	Missoula	15
Total Attendance			213

Persons attending these forums represented self-advocates, parent-advocates, staff and administrators of community based service providers, case management staff, teachers and persons interested in services for persons with disabilities.

Estimated percentages of persons attending these forums from each group is as follows:

Self-Advocate	75%
Parent - Advocate	5.6%
Provider Administration and staff	11.2%
Case Manager	.7%
Other Interested Person*	7.5%

*includes state agency personnel,
board members, teachers

TOTAL	100%
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At each Public Forum attendees were given the Montana toll-free phone numbers to reach both the Developmental Disabilities Planning and Advisory Council at 800/337-9942, and the Montana Advocacy Program at 800/245-4743.

Additionally, when issues of housing and housing modifications were raised at the forums, the Montana Advocacy Program shared that in the future there would be program to allow for some financial assistance in addressing modification needs. Details on the particulars of such a program are still in the planning stages, but when finalized, will be distributed statewide.

When issues were raised regarding Social Security benefits, the Montana Advocacy Program shared a recent program addition to their array of services. The PABSS (Protection and Advocacy for Beneficiaries of Social Security) program has just started with a full time advocate to assist persons who are experiencing problems with the social security system. The program funds may not be used to initiate litigation against the Social Security Administration. The program contact person is Kathy Kuntz, and she can be reached at 449-2344, or Montana toll-free 800/245-4743.

WRITTEN SURVEY TOOL

Approximately 3,700 copies of the Council developed written survey tool were disseminated statewide. The distribution list for the survey was based on the Council's standard mailing list, all provider corporations statewide, all People 1st Chapters, members of Partners in Policymaking and the PLUK (Parents Let's Unite for Kids) parent mailing list.

A total of 541 completed surveys were returned to Council offices. With a typical return rate of 5 - 7% on a written survey tool, the Council is very pleased with the participation level of this year's tool at 15%.

METNET STAKEHOLDERS PRIORITY SHARING OPPORTUNITY

On December 12, 2001 the METNET satellite downlink system was utilized to hold a statewide system stakeholder priority sharing opportunity. This opportunity allows for what is arguably, the only opportunity for all stakeholders in the service system to share their priorities, and hear other stakeholder's priorities all in one setting. The 2001 METNET opportunity

linked all METNET locations: Helena, Missoula, Bozeman, Billings, Kalispell, Great Falls, Butte, Havre, Warm Springs, Boulder, Dillon and Miles City. One VisionNet downlink location, Glasgow, was also utilized.

Stakeholders participating in this opportunity were:

The Disability Services Division	Joe Mathews presenting
The Developmental Disabilities Prog.	Jeff Sturm presenting
Independent Living Centers	Jim Meldrum/Pat Lockwood presenting
Montana Advocacy Program	Bernadette Franks-Ongoy presenting
MT Assoc of Independent Disability Services	David Eaton presenting
University Center for Excellence/RID	Timm Vogelsberg presenting
Office of Public Instruction	Bob Runkel presenting
People 1 st of Montana	Jason Billehous presenting
Partners in Policymaking	Jim Beyer presenting

Copies of stakeholders presentations are included in METNET Section of this report.

PUBLIC FORUM PRIORITIES

The following issues are those that were mentioned most frequently as priority issues across the forums. PLEASE NOTE, no attempt has been made to rank order the issues. Issues are listed in alphabetical order.

COMMUNITY LIVING

Need an Adult Level "PLUK" Organization - ARC

Loss of Food Stamps

Fuel Assistance Program

SSI/SSDI Issues - Income Limits

Individualized Budgets/Independence in Spending

Social Security/Marriage Issues

Independent Living Centers Need to Work More with Than Just People With Physical Disabilities

Lack of Adult Education Opportunities

Lack of Adult Education Arts and Crafts/Hobby Classes

Community Links for Education and Recreation

Ability to Access Provider Services in Home Community

CROSS CUTTING ISSUES

Transportation (Barrier to all Community Life)

Olmstead Implementation with Timelines

Build Services to Support People/Olmstead

Leisure/Recreation (Barrier to all Community Life)

Employment (Barrier to all Community Life)

EMPLOYMENT

Lack of Opportunities

Employer Training Needed

PASS Plan Training and Opportunities/Self Owned Business
Depressed Economic Conditions
Vocational Profiles
Career Path
Severely Disabled "Volunteer Work Plan"
Adequate Training to Be Competitive at Jobs People Want
Empower People with Disabilities to Make Informed Job Choices
Limited Job Market/Limited Industrial Opportunities
Lip Service by Employers (1 Hour of Work Per Work Day)

HOUSING

Lack of Housing
Lack of Affordable Housing
No Rentals for People with Physical Disabilities
Low Interest Loans/Adjust Regulations to accommodate larger families
Full Array of Housing Options/Ownership-Apartments-Condos
Funds for Housing in Good Locations
Home Ownership/Integrated/Affordable/Accessible
Models of Housing/Mail Plans and Maid Service

LEGISLATIVE

Provider Rate Increase
Direct Support Professionals - Living Wage
Maintenance of effort on infrastructure
Wage and Hour Respite Issue/Quality of Care
Funding for People 1st
Increased Funding for DD Programs
Increased Funding for Respite
Increased Funding for Crisis Situations
Increased Funding for Part C/funds equal the number served
Increased Funding for Families (youth aging out of services
Accessible License Plates and Hang Tags

RECREATION

Lack of Organized Opportunities/day trips - weekend trips
Important to Relationship Building
RAVE Program
Participation in Activities Builds Self-Esteem
People 1st Chapters - Funding
Lack of Transportation to Access Recreational Options
Y-Type Programs and Supports
Creative Community Links
Music and Arts
Teaching Programs/Educational and Hobby
Accessible Teen Center
Accessible Arcade

RESPITE

Wage and Hour Issue /\$430
Wage and Hour/Medicaid Revisit Interpretation
Wage and Hour/Congressional Review
Wage and Hour/HCFR findings "no decrease in service"
Respite is Incredibly Important to Sustain Families
Life Span Respite (Womb to Tomb Coverage)
Respite Keeps Youth and Adults in Natural Homes
Family Choice of Provider Issues
Crisis Management Tool
Respite House - Drop Off Services
Respite House for Crisis Intervention Before Psych Ward or
Institutionalization
More Youth will be referred for Out-of-Home Placement if Respite is
Reduced

TRANSITION/CHILDREN'S SERVICES

Youth aging out of services
Nothing to Transition to
Reduced Children's Resources
Lack of Family Choice
Child Care Center for Undiagnosed Mental Health Issues

Limited Nursing Options/Cost Containment
Funding for Smooth Transition/No Loss of Investment of Special Ed
Transition from Intensive Services to Adult Services
Employment/Faster Entry into Work
Socialization/Inclusion
Vocational Rehabilitation Involvement in Transition Earlier
Training for School Counselors
Funds Follow People
Funds for Youth to Buy Some Vocational Training
Collaboration Between Schools and Services
Stress on Families - Divorce and Illness
Crisis Driven System
Parent Training Needs
Lack of OT/PT Services in Rural Areas
PCA/Nursing Services to Support Children (and adults)
Limited Respite Funds
Waiting List Issues
Deteriorating Relationship Between DDP Central Office, Providers and Families

TRANSPORTATION

Lack of Transportation
No Transportation After 6:00PM or on Weekends
Excessive Cost of Other Options - Taxi's
No Coordination of Vehicles - Van Sharing
Lack of Adequate Funding for Transportation
Commercial Bus Service/Accessibility Issues
Training Needed for Community Education on Natural Supports for Transportation
Operational Costs

WAITING LIST

Crisis Driven System
Get People Off the Waiting List/Especially Intensive Needs
Families are Penalized Who Keep Their Family Member at Home
Children's Intensive Needs
Intensive Foster Care

WRITTEN SURVEY PRIORITIES

The written survey tool comprised of a listing of issues and asked the participant to identify their top three choices. If an issue was not included on the list the participant was asked to identify that issue under the "other" category.

The survey went on to ask the participant to tell us more about each of the three issues identified and what they would like to happen in regards to that issue.

For demographic purposes, the survey asked the participant to identify themselves as either a person with a developmental disability, a family member of a person with a developmental disability or a person working in the field of developmental disabilities. Again, for demographic purposes and to determine if we were reaching out to the diverse population we asked participants an optional question, that of ethnicity, either white, African American, Native American, Hispanic, Asian and Pacific Islander. Again, this was an optional question,

Lastly, we asked one additional optional question, the participants name and address. If that area of the survey was completed, the participant completing the survey will be sent a copy of the Final Report of the 2001 public information gathering activities.

The issues following are arranged by those areas being identified the most times by survey participants, and a selection of written comments on each issue by survey participants. A copy of the survey tool is included in this report as Appendix B.

The return rate for this survey was 15% with 541 completed surveys returned to Council offices of 3,700 disseminated.

Special Education - Identified 142 times

"Standards of competencies or proficiency established for individuals who provide direct instruction in specific disability skills; Braille, signing, orientation, mobility."

"It is important for teachers to understand learning disabilities and the need to follow IEP's better. Examples include cutting assignment sizes, changes in the way testing is performed. Middle School is the biggest problem."

"More funding for the schools and also for personnel to be trained better to work with the children and their families."

"Need training on Autism Spectrum and education." "Summer school programs."

"Improve special education offered in the school districts. Specify which schools offer the best programs for specific disabilities."

"Schools should be equipped to deal with special needs, very few in our town are."

"Too often schools work from limited budgets and offer bare minimum with a 'do what's required' attitude. Let's give these folks a great start and help them meet their full potential."

"More integration with regular peer population. Better representation for funding. I am very tired of these children being treated like the bottom of the barrel."

". . . children with FAS/E, the schools need to be aware of the problems of these children. All teachers and school systems do not seem to know how the FAS effects children in learning - discipline - socialization."

". . . keep special education programs in all the schools; elementary through high school. No funding cuts on these programs."

". . . need in-service trainings for regular education teachers on inclusion of special ed students." "Instruct the new teachers before they go out and teach. Get them while in college!"

". . . Special Education needs to be more family friendly and less time made on excuses to avoid giving needed services, especially "lack of money and resources".

". . . we have experienced the best and the worst of special education - something has to be done about quality control of services in each district."

". . . Special Education is often taught by people with the least experience. Aides are often used more as teachers, than as aides."

Employment - Identified 141 times

"...more opportunities to make a living and not have to rely so much on other sources (SSI, etc)."

"... more funds available for on the job training opportunities for students with disabilities."

"... a job is often the first step towards inclusion."

"... need a greater partnership between the schools, work-place and DD programs; need to start work-related training earlier in high school."

"... individuals with developmental disabilities need more and better job opportunities."

"More people working in the community."

"... being able to find a job that fits my disability."

"... selling employers on the idea of full time employment for persons with disabilities."

"... more education for the community to be more open minded about individuals with disabilities."

"... prevocational programs at high school level need to be emphasized."

"... everybody needs to have a chance to work, if they want to."

"... better paying entry level jobs."

"... my dream is to work. . . ."

"... information and support for a full range of post high school employment options."

"... to earn a living that allows me to live independently. . . ."

"... big issue in small towns - no jobs."

"... help for persons in small communities to gain and keep employment in the open job market, not sheltered workshops."

"... funds for support for a person once they are in the job."

"... we need more creativity in jobs. . . ."

Transportation - Identified 137 times

"... lack of transportation options." "...need transportation that fits my needs."

"... need longer hours of service, and weekends too." "... expanded service areas."

"...opportunities in rural communities." "...nothing outside the city limits."

"...more transportation opportunities at different times."

"...funding for more transportation options, support for grassroots level planning in town's throughout the state."

"...better transportation options, longer hours of service."

"...need transportation out of the city to another city for pleasure and medical care that isn't too expensive."

"...some people are independent at their jobs but are in services specifically for transportation."

"...choices and scheduling needs to be increased. . .without transportation you can access none of your other needs."

"...we need access to transportation in all areas of Montana. . .improve mass transit where available. . . co-op arrangements and rider boards."

"... persons with disabilities need available transportation 24 hours per day."

"... transportation to and from community events." "...transportation is a huge issue for many families and adults."

"...I want transportation that allows me to work after 4PM and be accessible to all individuals."

"...I would like to see people like myself be able to go places like to movies and special events in the evenings and Sundays. . . there must be some kind of transportation that people like myself can get to do this stuff."

"...coordination of services and services need to be expanded."

"...doesn't do any good to have funding for activities if you can't get there."

"...transportation that is available on an ongoing basis that is affordable for EVERYBODY. . . paying \$6.00 a ride to get to a minimum wage job for 2 hours is not affordable and is not accessible."

Waiting List for Disability Services- Identified 114 times

"...more services and opportunities for persons with developmental disabilities and their families."

"...waiting lists are ridiculous; there should be more facilities and funding for them."

"...try to create other opportunities such as post secondary programs."

"...find alternatives for families who need and want services, but are on waiting lists indefinitely."

"...state needs to fund services to eliminate the waiting list."

"...waiting list is a nightmare. . . . check out State of Washington model, call and find out how it works."

"...need more case managers. . . case loads of 30 instead of 50." ". . .entitled services."

"...everyone requesting services, receives them."

"...waiting list is outrageous!" ". . . waiting list is ridiculously long!"

"...people wait sometimes for years to get services. . . very difficult for families. . . sometimes families who provide a good home, can't get residential services. . ."

"...too many people go without services for too long. Everyone should not have to be in crisis to receive adequate services."

"...make sure services are available for all the people on the waiting list. It's a disgrace to Montana to have such a huge waiting list."

"...how long does a person have to wait. . . ."

"...seamless, efficient transition of young people from school services to immediate community services."

"...what do we have to do, wait until someone dies? . . . there are no services . . . this whole thing is a pitiful joke."

"...parents need real information on how long the waiting lists are and how limited local services may be."

"...I want off the list and in services!!!"

Direct Support Professionals - Identified 108 times

"...on-going efforts for education, support and increased salaried to attract and keep compassionate and competent caregivers."

"...care workers who are properly trained, have patience and understanding and respect persons with disabilities needs."

"...draw and keep good care staff; need to make it financially attractive."

"...see professionalism of the support staff work force."

"...direct support professionals need better pay... quality people cannot and will not stay in the profession if they cannot make a living..."

"...direct support professionals are not paid enough therefore quality of services is effected... we need higher pay to attract top quality people."

"...direct support professionals should be paid enough to keep them in their positions... they should receive health care benefits."

"...paid what they are worth so that good quality, consistent staff are still around."

"... wages on par with MDC."

"...we tried hard to work with the legislature/Governor... we will achieve equity in pay in the year 2050... it's time to sue the state."

"...make this vocation a professional, respected one that draws people as their first choice instead of their last choice for employment."

"...higher standards/more qualified direct care professionals; better applicant screening procedures."

Accessible and Affordable Housing - Identified 106 times

"... stable living situations, either house or group home, with well trained and suitably paid staff."

"...the thought to enable people to afford to live independently."

"...group homes with residents more similar to each other, i.e. age, interests, etc."

"...due to cut-backs in food stamps and medical coverage, rents must be adjusted accordingly."

"...integrated, affordable community housing - individual, group, apartment and assisted living."

"...affordable housing is not always safe or desirable. ...people with disabilities should not be relegated to tenements because they can't afford a better place."

"...provide loans to persons with developmental disabilities."

"...energy assistance programs ...small condos."

"...re-evaluate food stamp cuts for individuals living in group homes."

"...substandard housing is all that I can afford."

Quality of Disability Services - Identified 100 times

"...extend access to school; college opportunities. State of Washington has a program for people with disabilities in their community college."

"...need more drop-in, surprise inspections of facilities. Seek input from staff on a confidential, non-retaliatory basis."

"...need increased training and quality of staff. ...start by increasing requirements and pay."

"...not all services are top quality - mainly due to financial restraints."

"...would like to see direct support professionals have better training opportunities and increased wages."

"...community providers should be held accountable and have surveys like the institutions."

"...better monitoring of disability service providers and the dispersion of money within agencies."

"...quality of services in outlying rural services seems to be non-existent. ...want to know more about micro boards."

"...this is always a concern, and always will be."

"...lack of qualified people in rural areas to do things like OT, PT, Speech, etc. ...this limits the quality of disability services especially for children who in many cases need it the most."

"... with portable funds, services that are not doing a good job will be forced to improve or fold because of competition from superior services that will attract customers with portable dollars."

"...overall quality of services to disabled need to greatly improve."

Early Intervention - Identified 97 times

"...difficulty knowing what services are available; parent training needed."

"...make services and availability more known, currently a "best kept secret."

"... early intervention is essential to identify needs before they become overwhelming."

"...families of all income levels should be able to access every opportunity available for diagnosis and early treatment."

"...kids need to be evaluated early and annually. . ."

"...Montana does not meet IDEA (National Council on Disabilities and experience with my school district). This must change, the state has a poor public school system."

"...state must provide for alternative schools, either public or private."

"...hearing checks for newborns. . . would have given us almost 9 months of time."

"...quality substandard compared to other cities of same size. . . the knowledge level of newer and effective therapies is not possessed. Pediatricians, PT's, OT's and speech therapists in this area are very outdated. Therapies, if applied at an early age can save millions of disability dollars in the future, let alone the pain and suffering of the individual and the family. Get the "professionals" in these areas up-to-date!"

"...more FTE's at state administration level to support the Part C Coordinator. . . more funding to support FE&S and IFE&S services to families who need them."

"...families will need help from DDPAC, MAP and other disability organizations to help advocate to DPHHS Administrators, state and federal legislators for changes needed."

Respite Care That Meets My Needs - Identified 86 times

"...needs to be more flexible."

"...easy access to respite care and be able to have more than one choice of providers."

"...this is what keeps good parents good."

"...desperately needed and difficult to find. . . . funding for multiple Respite Care Homes statewide."

"...more recruiting and basic training."

"...respite care that is reliable, affordable and achievable. . . . medical knowledge needed."

"...many families utilize the respite reimbursement and are alarmed it may no longer be available."

"...respite care that remains up to the family, not the professionals. Check out the State of Oregon model, funds go direct to the family so they may choose what is best for the child."

"...respite care that is based on the persons needs. . . . it is very difficult for families to run their respite care through an agency."

"...respite services are critical to families trying to keep their children at home."

"...caregivers need to be given many options and encouraged to use them."

"...respite is critical to keep parents sane and children safe. . . . high burnout if families are not given a break."

"...enough funding for respite care - it is exhausting for families to take care of a child with a disability - it literally takes your life away from you."

"...keep respite care available to families by friends and relatives and others to keep affordable and able to meet the needs of the person and the family."

Getting the Health Care I Need - Identified 80 times

"...need more qualified health care assistants."

"... need someone to help guide us through legal and insurance paperwork, and to tell us where to go for help."

"...medication is very expensive. . . .care for my child doesn't exist in terms of childcare. . . . health services don't exist for those who haven't the means to pay. . . ."

"... medical professional education, i.e. workshops on working with persons with developmental disabilities."

"...nationalization of health care."

"... more information and services need to be known to all communities, especially underserved populations."

"...adequate health care professionals, especially in the areas of mental health concerns."

"...affordable services, affordable prescription medications."

"...as we get older, the more care I believe we need."

"...not all doctors remember their Hippocratic Oath when it comes to dealing with persons with disabilities."

"...appropriate health care can be very difficult to find in a small community. . . better availability of OT/PT and specialists would be extremely helpful."

Making and Keeping New Friends - Identified 67 times

"...socialization opportunities listed and provided on request to those who want to be on a mailing list."

"...people need to have opportunities to meet people and develop friendships."

"... recognize the importance of the social aspect of an individuals life and place more emphasis on developing programs and/or activities that will enhance this."

"...structured opportunities to develop/maintain meaningful friendships within the community."

"...develop with the schools a "circle of friends" system to assist kids in making friends in and out of school."

Understanding Financial Benefits (SSI/SSDI) - 65 times

"...what financial assistance is available when he/she is an adult?"

"... help me understand what is available."

"...knowing what's out there, if I'm eligible, how to apply and help in applying if I need it."

"...help in filling out paperwork."

"...benefits being cut due to marriage."

"...I learned more in a book I had to purchase than I did from case workers. . . some people are quick to say you're not eligible but not very informative on what you can do or are eligible for."

"...we need more workshops with presenters who can clearly in lay-persons language explain how best to make this work for your specific person."

"...training for parents, staff, guardians etc., regionally - once or so a year."

Recreation Choices in My Community - Identified 56 times

"...access to facilities that maintain physical movement and foster opportunities for communication and relationships."

"...don't have many choices here, only going out to eat."

"...some people need help to know what is available. . . they may not want to do it alone, they may want a companion to go with them."

"...recreational directory would be great."

Being Included in My Community - Identified 51 time

"...be a part of the community, "run, play, work"; sought out in their church. . ."

"...philosophical issues of inclusion detracts from the limited resources available. I would like to see a service model that allows for consensus among the divergent camps."

In-Home Assistance - Identified 50 times

"... small town problem, opportunities are not available."

"...services need to be evaluated on a case-by-case basis rather than forcing families into what's available for resources and funding."

Directing My Own Support Needs - Identified 38 times

"...we need support from local human service offices. . . we're told "sorry and good luck"."

"...a system designed around the individuals needs and desires."

"...create training and support to consumers, families and communities that demonstrates self-determination to follow the person."

"...portability of funds."

"...people in need of disability services have to learn how to be their own advocate - this will ensure understanding of services and what they should be receiving."

"...families/persons with disabilities need to be able to have a budget and decide the best way to use it. ... families need well trained, educated and efficient advocates and consultants."

"...assist with education so people can self-direct. ... education needs to include responsibilities and informed decisions."

"...many professionals do not include the client to the extent of choosing and having input to what they need. ... the "we know best" attitude is more obvious in the dd system than any other."

"...I need more control over my life." "...I want to be more in charge of selecting my yearly objectives."

"...support and training so people can direct their own lives."

Feeling Safe in My Community - Identified 34 times

"...staff that is fully alert, both day and night..."

"...review and emphasis on who to protect oneself. ... how to identify safe versus dangerous situations. ... how to respond in crisis."

"...being a responsible member of my community."

"...streetlights that work, sidewalks that aren't falling apart."

"...continue the small town values, rather than big city chaos."

"...a safe place to feel equal, safe and understood."

"...I want to be safe from bad people"

"...training on sexuality and socialization issues for individuals served. This is a chronic, severe problem for many individuals, either as victims or perpetrators. This needs to be more than a hit and miss approach."

Developing Leadership - Identified 30 times

"... individuals with disabilities are excellent spokespeople for themselves and their issues."

"... educational and informational opportunities for persons with disabilities to enable self-advocacy as well as peer advocacy."

"... support self-determination efforts at all levels."

"... organizations like People 1st should be supported and developed to assist adults with disabilities become even more self-sufficient."

"... develop leadership skills that will empower friends/advocates/guardians/consumers to stand up for what they want."

"... guide on rights and responsibilities. . . guide on the role of advocates/guardians."

Feeling Safe in My Home - Identified 28 times

"... staff that is fully alert, both day and night. . ."

"... not wanting to be bothered by others. . . provide safety checks, automatic lights, doorbells."

"... need training on how to recognize and handle situations of harassment and abuse."

Personal Assistant Services - Identified 27 times

"... more people available to help individuals who wish to live in their homes, not group home settings."

"... need a more organized way of finding personal care attendants; way too many scattered lists floating around. . . need more full time affordable people, and the funds to pay for them."

"... personal care attendant services available at the times needed."

"... as persons with disabilities age more will need these services. . . if services can be received before they age they can learn good nutrition and exercise habits that will enhance their lives a great deal."

"... without knowing what we qualify for or how to get it there are so many holes in the services. . . it seems like a very reactive versus proactive way to take care of ones needs."

"...one severe problem that families have is obtaining and keeping good PCA workers - the turn over rate is phenomenal. All workers who provide direct care should receive the same pay as state workers."

Information on Assistive Technology - Identified 21 times

"...with assistive technology many individuals could be successful beyond their expectations. Get the word out of all the advancements."

"...more information on current technologies used around the country - keep more up-to-date."

"...educating parents, teachers, everyone involved with the child on the possibilities."

"...there needs to be more funding available and utilization and acceptance in the classroom."

"...many people are unaware of what is available to them. . .if there is knowledge then they don't have access or information to get these items. . . cost is a big factor as well."

"...increased use and availability of assistive technology."

Understanding Aging Services Available - Identified 21 times

"... more cooperation between long term care division and developmental disabilities program."

"...what services are available?"

"...better understanding of aging services for persons with disabilities and providers."

"...increase media coverage of local services."

Helping People of Different Cultures be More Comfortable in the Community - Identified 5 times

"...we will all face issues of race and culture. . .with the war that has just started this will be a touchy subject especially for individuals with developmental disabilities and who are of eastern descent. . .we should make an effort to educate everyone to be accepting."

Other Issues - Identified 63 times

"More men helping with men who are disabled."

"Dual Diagnosis = self-esteem issues."

"Being a responsible member of the community."

"Large enough budgets to support/accommodate independent living in the community."

"Sex offender intervention and therapy."

"Empty the Institutions."

"In-school mental health counseling that works with students and their families."

"Portable money for services where I want to live."

"Individualized supports need to happen and hopefully the group in charge to that can believe it can work."

"Services that come and go because they are grant dependent."

"More dollars available for follow-along services for community jobs (VR)."

"Take the discussion to community leaders. . .as long as our efforts focus on the system, you will only be able to accomplish what the system wants you to accomplish."

"Re-evaluate food stamp cuts for individuals living in group homes."

"Choice and portability - see that this happens in a way that actually facilitates client choice and portability - and see that it happens in an administratively efficient way."

"Brokerage services"

"Our state needs a place for dd people in crisis without ending up with a year long commitment."

"Protection of the ADA."

"Assistance for families whose child is not yet diagnosed dd and make only a few dollars too much to receive financial assistance, but yet have to pay for medication and the many Dr. visits needed to care for their child."

"Expedite research in the field of Autism and Chronic Fatigue Immune Syndrome, Fibromyalgia."

"Financial support for people with disabilities to attend the DD Conference."

"Check out Idaho - they have great programs that keep people from being warehoused in rest homes, hospitals and group homes!"

"Management of DD Service Agencies; noted professionals in the field continue to stress service delivery is people management. It is a more important factor than staff turnover, low wages, etc., and often the most overlooked. Many other industries (eg: fast food restaurants) are faced with these same issues but they keep their performance fairly high through emphasis on quality management."

"Health and wellness issues are critical to all. Oral and dental health, nutrition, physical fitness, etc."

"The need for comprehensive socio-sexual skills training, information regarding dating, trust and relationships."

"Adequate funding for providers to cover the costs of operating expenses."

"The Department is making lots of program and policy changes without including consumers (not vendors, consumers). This move away from including stakeholders can only diminish the quality of services. . . "

METNET PRESENTATIONS

All stakeholders who presented are listed below, however some stakeholders did not respond to the Council's request for a written copy of their text, and as such a copy of their written priorities/input is not included in this report.

Copies of the presentations submitted by the following METNET Stakeholders are attached to, and become a part of this report.

Disability Services Division, Joe Mathews
Developmental Disabilities Program, Jeff Strum
Office of Public Instruction, Bob Runkel
UCE/Rural Institute on Disabilities, Timm Vogelsberg
Montana Advocacy Program, Bernadette Franks-Ongoy
MT Association of Independent Disability Services, David Eaton
Parents Let's Unite for Kids, Dennis Moore
People 1st of Montana, Jason Billehous
Partners in Policymaking, Jim Beyer

Additionally, input was requested from any persons present at any of the downlink locations. Copies of their input is also attached and made a part of this report.

Region I Manager, Dain Christainson
STEP, Inc., Joan Grauman and Sue Dow
Job Connection, Inc., Rita Schilling

Comments for DDPAC Teleconference

**Joe Mathews, Administrator,
Disability Services Division**

- **Thanks to DDPAC and the Montana Advocacy Program for their efforts in doing these forums**
- **The budgeting process for the 2003 Legislature is beginning. We will begin the process of developing our priorities within the next couple of months.**
- **We have been told by the Governor's Budget Office not to expect much in terms of new proposals getting into the Governor's budget. As of now, any new proposal will have to be accompanied by a like amount of cuts in General funds for it to be considered.**
- **The world of services to people with developmental disabilities is changing; the State of Montana will continue to work toward choice models of services and will be re-emphasizing its quality assurance responsibilities as per our review from our federal Medicaid partner.**
- **We anticipate talking with the Legislature about our continuous infrastructure problems and the need for provider rate increases, the possibility of some expansion to lower our waiting list, the continued movement at a reasonable pace of individuals referred to community services from our residential facilities, the need for crisis dollars, lifespan respite services just to name a few.**
- **Vocational Rehabilitation will be looking at maximizing our ability to fully match our federal grant.**
- **If we were able to ask for more staff (a big if at this point) we would look at case managers in DD and VR Counselors in VR.**
- **The state Medicaid budget is in serious trouble and that will have an effect on all other budgets within the department. There is a possibility that some or all of the DD refinancing \$\$--(general fund) will have to be given up to help the department balance its overall budget. This could seriously affect movement of persons from residential facilities and our ability to move more people off the community waiting list during this next year.**
- **We look forward to working with the disability community on our funding requests and we will utilize the information we have received to help us prioritize which requests will be most essential**
- **We again appreciate the state wide assessment process. These programs are noted for listening to the various constituencies that we serve and then**

developing our planning in conjunction with the priorities that emerge from meetings such as this. We will certainly continue to do that.

DEVELOPMENTAL DISABILITIES

PROGRAM PRIORITIES

FOR 2002- 2003

(as presented at the DD/PAC stakeholders met net 12/12/01)

GOALS

- 1) Develop a system of reimbursement that allows choice and portability to consumers and families. This includes developing a qualified provider application and review process to offer consumers more choice of providers
- 2) Redefine quality assurance and develop a process that assures the health and safety of consumers
- 3) Continue to identify consumers in our 2 ICF/MR facilities (Montana Developmental Center (MDC) and Eastmont) for placement in the community
- 4) Review current commitment laws and recommend changes as necessary
- 5) Refinance all potential clients currently funded under general fund to Medicaid to maximize funds available to serve consumers
- 6) Provide medication safety training to all direct care staff

PLANS/TIMELINES

- 1) Establish qualified provider guidelines for both adult and children services by 7/02
- 2) Establish a payment/reimbursement system that allows funds to move with a consumer that choose to move to another provider.
Phase 1 (limited Medicaid services) by 7/02,
Phase 2 (all Medicaid funded services) by 7/03
- 3) Review and recommend changes to the Quality Assurance process, including the review of current policies and practices, reporting requirements, and establishing a sanction policy by 7/02
- 4) Use refinancing dollars to move up to 15 people out of MDC and Eastmont by 12/31/02
- 5) Use refinancing dollars to move additional people off of the community waiting lists by 1/1/03
- 6) Establish a work group to review current commitment laws: First meeting 12/01
- 7) Refinance all general fund services. Work day and transportation services have been refinanced. Supportive living and children services will be refinanced by 12/02
- 8) Update rules to comply with system changes completed by 6/03

POSSIBLE EXECUTIVE PLANNING PROCCES (EPP) PROPOSALS

- 1) Request additional funds to move consumers from MDC, Eastmont and the waiting list
- 2) Request a provider rate increase for salaries etc., and to compensate for the losses from cuts to LEAPP and Food stamps
- 3) Request additional Casemanagers, and Field Service Specialists
- 4) Request additional crisis funds
- 5) Request funds to continue psychotropic medication consultation training/grant
- 6) Request funds to develop a transitional program to successfully move clients with a history of sexual offenses to the community
- 7) Establish Enterprise entity at MDC to assist in the development of client industries program
- 8) Increase Community Supports cap to adjust for increased costs.
Current cap is at \$7800

Presentation of Bob Runkel
Office of Public Instruction
December 12, 2001
METNET Priorities Sharing Opportunity

Thank you, Deborah, for the opportunity to report on some of the priorities of the Office of Public Instruction for the year. I need to share that I served as a member on the Developmental Disabilities Planning and Advisory Council for ten years, and that it was a very positive experience. My name is Bob Runkel, and I am the Director of Special Education/Division of Special Education for the Office of Public Instruction.

Accomplishments

- State Plan submitted and approved by the United States Department of Education.
- Approved State Improvement Plan following the monitoring by the United States Department of Education.
- Transition Outcomes Project. Schools involved in the transition outcomes project have shown substantial improvement.
- We Teach All. The We Teach All project has been very popular in schools. The project helps general educators be more effective in teaching children with diverse learning needs.
- Montana Behavioral Initiative. The Montana Behavioral Initiative continues to grow. Over 800 teachers, administrators, and agency personnel participated in the summer institute.

Priorities

1. Continue to improve public school accountability for the performance of students with disabilities through:
 - effective monitoring practices for schools that are sensitive to student outcomes;
 - reporting to the public of the performance of students with disabilities; and
 - improved access for children with disabilities to the general education curriculum.
2. Increased funding for special education:
 - Federal Funds—hopefully, federal funding will increase to 40 percent of the national average per pupil expenditure. This could mean additional millions of dollars for Montana's children with disabilities.
 - State Funds—it will be important to monitor the recommendations of an interim committee now studying state education funding structures.
 - Medicaid—Medicaid holds promise for increased funding for Montana. Montana currently does not generate as much revenue for Montana schools as would be typical in other states of similar size.
 - Balance—the cost of special education is high. It is important that there be a balance between the contributions of state, federal and local sources.
3. Professional Development:
 - Technical Assistance—on-time availability of technical assistance to schools serving children with low incidence disabilities.
 - Web Site—improved design to the OPI Web site enabling parents and educators to more easily find information available.

- Integration with General Education—training activities that include a higher proportion of general education staff that support their development of skills for serving students with disabilities.
4. Reauthorization of Special Education IDEA Act
- Monitor to be prepared for change in the following five areas:
 - Paper work
 - Discipline
 - Funding
 - General education
 - Early Intervention—especially mild disabilities

This will be an exciting and challenging year, which holds great promise for the future of education for children.

Thank you DDPAC, Deborah, and other presenters for this opportunity to share ideas, and to support one another in our priorities.

**Developmental Disabilities Planning Council Presentation
MetNet - December 12, 2001**

OUR FUTURE SUPPORTING PEOPLE WHO HAVE DISABILITIES

by R. Timm Vogelsberg

The University of Montana's Rural Institute is Montana's federally supported Center for Excellence in Education, Research, and Services. We have a federal mandate to support school and community inclusion as the best practice for individuals who have disabilities regardless of age or level of disability. This is a value which we work hard to share and promote. As a professional and a family member my life experiences have convinced me that we must all learn to listen, collaborate, and move forward as quickly as we can. I am frequently astonished that services which we envisioned for people with disabilities twenty years ago are still an unrealized dream. Preparing this paper was difficult because the message is similar to things we wrote in the 1970's. It was a reminder of how far we have to go.

In previous years I attended workshops on collaborative teaming and inclusive education in Vermont. Vermont and The Rural Institute supported inclusion teams from different school districts to attend four day workshops to learn more about collaborative teaming to assure inclusive outcomes for a student with a severe disability. Members of the team included: a family member, regular educator, special educator, principal, behavior specialist, district administrator, and two university people. These workshops were wonderful experiences that focused on collaborative teaming and inclusion plans for one child (easy for family members but hard for teachers and administrators). The expectation that if you can work out the system to support one student - and then another student - that eventually you will have identified all of the system issues while you are actually supporting individual students. It avoids the difficulty of thinking about how to include every child tomorrow and makes the whole process much more workable.

We visited responsive school sites - where students were fully included - always a part of the regular classroom. The major difference between many Montana current activities was in the starting point. Questions are never raised about where the student goes to school - it's where all students in that community go to school. Long range planning was continually available to assure that needed adult services were available once the student left school services. The whole attitude was focused on how to deal with all support issues within an inclusive setting. Vermont has truly understood the difference between supports and program locations. They've mirrored the same process within supported employment and supported living settings.

Just as education has a strong movement towards the utilization of generic services (regular not special) this practice is being adopted at the adult level. We have to

recognize that this change is coming - with or without our involvement and support.

Rural Institute Efforts in Research, Teaching, and Service

Our research, teaching, and services are guided by the Developmental Disabilities Act Amendments and our ability to secure external funding to meet our mission. A short listing of some of our priorities for the coming years in research, teaching, and service is identified below.

Research

- Health:** We're working with the Department of Health and Human Services, including the Health Services Division and the Disability Services Division, to develop a grant proposal to the Centers for Disease Control to establish a state-based Disability and Health Program

- Transportation:** We're working in collaboration with the Association of Program for Rural Independent Living, we secured a Transportation Demonstration grant from RSA. One of the named sites is the Montana Transportation Partnership so we expect to be working on rural transportation issues with at least one community over the next five years.

Teaching

- We're expanding access to teachers and others who work with people who experience severe disabilities. Increased efforts to provide support and instruction to individuals supporting people who experience disabilities through Distance Education. The Rural Institute will expand the use of asynchronous and synchronous distance training opportunities.

Service

- Employment:** We're working to improve and expand community employment opportunities for individuals with disabilities

- Social Security Work Incentives:** We want to promote increased use of Social Security Work Incentives to increase community employment opportunities for individuals with disabilities

- Child Find:** We're working to improve Child Find and research in Early Intervention:

- Education:** We're supporting Montana's State Improvement Grant as determined by the Office of Public Instruction.

- Assistive Technology:** We're improving services through evaluations and access to Assistive Technology

Desired Service Goal for the Future:

Support the development and Implementation of a five year multi-agency specific plan to expand the quantity and quality of existing efforts focused on school and community inclusion, empowerment, and family-consumer control.

Suggestions for Future Consideration:

The amount of consensus in direction is wonderful - the challenge is in accepting the necessity to change and in negotiating the timetable for change to occur. For our system of supports for people who experience disabilities to grow, I believe that we need to recognize and implement at least the following things:

1. **Consumer Control:** Recognize that the service system has moved through three distinct periods: (1) professional control; (2) family control; and now (3) consumer control. We all need to get to #3. Many professionals (myself included) need to recognize and support this reality.
2. **Choice:** We need to work in early ages to assure that individuals understand choice, have opportunities to make choices, and learn to utilize their own independent decisions as much as possible. Support to learn about self-determination, self-advocacy, and multiple opportunities to make informed choices must be supported.
3. **Consumer Participation:** Assure consumer participation on all Advisory Boards and Boards of Directors. The input of the families and individuals gaining support is crucial. The proportion should be at least 50 x 50.
4. **Change Culture:** We need to accept and value change. Change is with us and will continue to be with us. We can embrace and grow with it or we can resist it. Staying in the same place denies the progress which is possible. As we learn from competitive business spokesperson Tom Peters,

If you aren't getting better faster than the other guy - you're getting worse.

Funds, services, and politics are increasingly competitive. To survive we must learn to deal with the changes coming our way and learn to utilize them to the best advantage possible for people who have disabilities.

This Change Culture Should Focus On Incentive Based Change: We need to create an incentive based system which supports inclusive community settings. Proven approaches in other states include:

- Direct all expansion funds to community inclusion
- Gradually increase agency budget supports for community inclusion
- Develop higher reimbursement rates for inclusive community supports

5. **Expand and Increase Community Services Support:** Create a mobile family-consumer voucher system to purchase all community services. Having a menu of multiple options which are less restrictive and less expensive has been proven to actually save funds. We must avoid the full service (most expensive service) or no service approach.
6. **Diversity:** Recognize and value diversity in all forms (race, culture, language, disability, and-or sexuality).
7. **Natural Proportions:** We should establish a natural proportions (10%) hiring goal for all private and non-profit employers - including government and universities. Our Institute currently has 17% employees who experience some form of a disability.

This same orientation - natural proportions - should be our guide for education, recreation, employment, and all activities. If 10-15% of the population experiences a disability then school and community activities should reflect a similar proportion.

8. **Implement Olmstead - Avoid Future Lawsuits:** We all continually discuss how limited resources are in Montana - to waste any of these resources on legal expenses instead of implementing federally driven regulations is just not judicious use of limited resources. Settle the law suit, adhere to federal initiatives, and provide services as the first priority.
9. **Homecoming:** Return those individuals who are currently excluded in institutions to their home communities and support them in inclusive settings. Al Smith (MAP's previous Exec.) told us clearly,

Only criminals should be excluded.

Proven approaches in other states which have closed their institutions include at least the following:

Support, expand, and improve the community system
Stop the backfilling - replacing those who leave with new residents

10. **Transportation:** Implement rural transportation solutions - such as voucher systems - within rural settings.
11. **Waiting Lists:** Assure that no student leaving school is assigned to a waiting list. Establish effective long term planning and adopt under - utilized options. We must recognize the reality of limited resources and utilize all options to the fullest to avoid waiting lists. Social Security and Social Security Work Incentives are strong options that are currently underutilized.

12. **Aging:** Expand opportunities for individuals who have disabilities and are aging into multiple community inclusive settings. Communities for people who are aging are becoming more inclusive, less “nursing home institutions”, and following the same lines of community inclusion as education and the adult services.

Finally, we must all accept that it is our responsibility to inform legislators about the support needs of families and consumers. It's so easy to expect State Department Administrators to advocate for funds, If we expect more resources we must share the responsibility to inform legislators and voters.

Thank you for this opportunity to provide input. This expansion to the Developmental Disabilities forums has been an excellent opportunity to learn just how much we all agree. We continue to face the exciting opportunity to support future change and improvement of supports for people who experience a disability.

Fiscal Year 2002 Priorities

Adopted by the Board of Directors 10-26-2001



A. CORE SERVICES UNIT

Vision Statement

Staff will provide accurate and timely information, referral, outreach, training, advocacy and / or legal services to people who make contact with MAP.

	Objective	Activity	Program Resource Allocation					
			PAIMI	PADD	PAIR	CAP	AT	PABSS
1.02	People with disabilities, non-disabled persons and persons with disabilities with ineligible issues will receive reliable, timely information and referral services.	Advocacy	X	X	X	X	X	X
		Service Request						
2.02	Advocacy services for non-priority issues will be provided to eligible persons with disabilities in accordance with intake case selection criteria and with in existing resources.	Advocacy Legal	X	X	X	X	X	X
		Service Request						
3.02	Develop and implement a needs assessment to determine who is un-served or underserved by MAP.	Outreach Advocacy	X	X	X	X	X	X
		Project						
4.02	Outreach and training services will be provided on a quarterly basis to minority and underserved person with disabilities, as identified in needs assessment.	Outreach Training Advocacy	X	X	X	X	X	X
		Project						
5.02	Resource library will be expanded and maintained to provide resource information to persons with disabilities and their families.	Advocacy Legal	X	X	X	X	X	X
		Project						
6.02	Develop facts sheets for the most requested rights related issues that effect persons with disabilities.	Legal	X	X	X	X	X	X
		Project						

B. ABUSE & NEGLECT

Vision Statement

To protect and advocate for the right of people with disabilities to live free from abuse and neglect while residing in care and treatment facilities.

	Objective	Activity	Program Resource Allocation				
			PAIMI	PADD	PAIR	CAP	AT
1.02	Review all PADD & PAIMI eligible allegations of abuse and neglect, including death, seclusion, physical, chemical or mechanical restraints. If referral meets case acceptance criteria, MAP may analyze, investigate, and pursue remedies including, but not limited to advocacy, administrative remedies, law suits and appeals.	Legal	X	X			
		Service Request					
2.02	Monitor select facilities regarding abuse, neglect, restraint and seclusion.	Legal	X	X			
		Project					
3.02	Participate in task forces to improve the safety of persons with disabilities living in care and treatment facilities.	Advocacy	X	X			
		Legal Project					

FY2002 Adopted by BOD 10-26-01

C. ACCESS VIOLATIONS / DISCRIMINATION / AT

Vision Statement

Private and public entities will comply with the Americans with Disabilities Act, the Rehabilitation Act (Section 504), the Montana Human Rights Act, and the Fair Housing Act as those laws promote and maintain accessibility. Individuals will have access to Assistive Technology to promote independent living.

	Objectives	Activity	Program Resource Allocation				
			PADD	PAIMI	PAIR	CAP	AT
1.02	Review cases that allege discrimination on the basis of disability including the failure to provide meaningful access to the services or benefits offered by a public entity or private facility or the failure to provide appropriate access to housing to determine the appropriate level of MAP services.	Advocacy Legal		X	X		X
		Service Request					
2.02	Review cases that involve the denial of assistive technology for persons with disabilities by Medicaid, Medicare, and Special Education to determine the appropriate level of MAP services.	Advocacy Legal			X		X
		Service Request					
3.02	Provide short-term assistance and technical assistance for disability related discrimination and AT cases.	Advocacy Legal		X	X		X
		Service Request					
4.02	Complete the survey of Montana Courthouses to determine accessibility, compile the information, and write a report.	Outreach Advocacy			X		X
		Project					
5.02	Continue to monitor the implementation of the <i>Salmond</i> settlement agreement.	Legal			X		X
		Service Request					
6.02	Represent individuals who have been discriminated against by public or private entities through failure to provide meaningful access to the benefits and services they offer or failure to provide housing access, using such individualized strategies as filing administrative complaints, lawsuits and appeals, in accordance with case selection criteria.	Legal		X	X		X
		Service Request					
7.02	Represent individuals who have been denied assistive technology by Medicaid, Medicare or the educational system, using such individualized strategies as filing administrative complaints, in accordance with case selection criteria.	Legal			X		X
		Service Request					

D. COMMUNITY INTEGRATION

Vision Statement

People with disabilities will live, work and recreate in communities of their choice with the supports and opportunities to participate as equal members.

	Objectives	Activity	Program Resource Allocation				
			PADD	PAIMI	PAIR	CAP	AT
1.02	Represent children diagnosed with SED who are being placed, or are at risk of being placed in residential treatment, other care/treatment facilities and juvenile detention centers; to obtain appropriate community mental health services, in accordance with case selection criteria.	Advocacy Legal	X	X			
		Service Request					
2.02	Respond to significant developments in the Mental Health Services Plan that affect children and adults with mental illness, through strategies to be developed.	Policy		X			
		Project					
3.02	Participate in selected policy forums and engage in advocacy activities on selected issues.	Policy		X			
		Project					
4.02	Advocate for mandatory training for probation officers, detention center and/or jail workers on the rights and needs of children and adults with mental illness.	Policy		X			
		Project					
5.02	Continue class action litigation, Travis D, and other related individual cases or activities to obtain appropriate community services for individuals with developmental disabilities.	Legal	X				
		Service Request					
6.02	Provide education and other support to facilitate grass roots advocacy by persons with disabilities and other advocates in implementing the Olmstead decision.	Advocacy Training	X	X	X		
		Project					
7.02	Participate in state level policy committees to design and maintain Olmstead plans—Senior Long term Care, Disability Services Division and Addictive and Mental Disorders Division.	Policy	X	X	X		
		Project					
8.02	Challenge unconstitutional provisions of civil commitment laws through selective impact litigation (As legal resources allow).	Legal	X	X			
		Service Request or Project					

E. EMPLOYMENT

Vision Statement

People with disabilities have a choice of meaningful employment, which is free of discrimination and maximizes their employment capacity.

	Objectives	Activity	Program Resource Allocation					
			PADD	PAIMI	PAIR	CAP	AT	PABSS
1.02	Review cases alleging employment discrimination based upon disability that present legal issues with systemic impact to determine appropriate level of MAP services.	Advocacy Legal			X	X		X
		Service Request						
2.02	Provide short term and technical assistance to for disability related employment cases.	Advocacy Legal			X	X		X
		Service Request						
3.02	File administrative complaints, appeals and lawsuits on behalf of people with disabilities that allege employment discrimination in selected cases.	Advocacy Legal			X	X		X
		Service Request						
4.02	Provide public education on Title I of ADA so individuals with disabilities may know their rights related to discrimination in employment.	Outreach Advocacy			X	X		X
		Project						
5.02	Represent qualified individuals in accordance with CAP program requirements.	Advocacy Legal				X		
		Service Request						
6.02	Provide information and referral to SSB about work incentives and employment	Advocacy						X
		Service Request						
7.02	Provide assistance and individual representation to SSB who are seeking rehabilitation, employment and other services from employment network and other services providers.	Advocacy Legal				X		X
		Service Request						
8.02	Provide consultation to and legal representation on behalf of SSB with disabilities to protect their rights.	Legal						X
		Service Request						
9.02	Identify and advocate to correct deficiencies in entities providing vocational rehabilitation, employment and other support services to SSB with disabilities	Policy						X
		Project						
10.02	Maintain seat on the State Vocational Rehabilitation Council.	Advocacy Policy				X		X
		Project						

F. Civil Rights Protection

Vision Statement

The civil rights of people with disabilities will be protected and defended.

Objective	Activity	Program Resource Allocation					
		PAIMI	PADD	PAIR	CAP	AT	PABSS
It is foreseen that the civil rights of people with disabilities will be violated and MAP may need to respond when issues are presented. This objective may be used only in accordance with the established criteria and the approval of the executive director.	Legal	X	X	X	X	X	X
	Service Request						

FY2002 Approved by BOD 10-26-01



Montana

Association

of Independent

Disabilities

Services, Inc.

To: Deborah Swingley,DDPAC

From: David Eaton, MAIDS

METNET Stakeholders Priority Sharing Opportunity: December 12.

Montana Association of Independent Disabilities Services (MAIDS) Priorities:

1. Rate Increases: In order to ensure the health, safety and well being of consumers our number one priority is adequate annual rate increases. During the last session the State Legislature took a bold first step to address the low rates of compensation paid to community based direct care employees. Adequate annual rate increases would enable providers to continue to substantially increase direct care staff compensation and would allow providers to keep up with the increasing cost of doing business. We aim to determine by Summer what exactly those rate increases should be.

2. Service Expansion: For the last 25 years MAIDS has been a supporter of this concept. We have always attempted to find a balance between maintaining the quality of our existing services and the health of our infrastructure, while supporting service expansion. MAIDS will continue to be actively involved in the overall expansion of services for Montanans with disabilities. We are committed to providing services to people who are leaving the institutions and to people who live in communities across Montana but receive no services.

3. Individualized Services: We believe that over the last quarter century or so Montana has established an effective service system and the concept of individualized services would only improve upon that system. MAIDS will continue to work with the State of Montana and the other stake holders in our system to craft a carefully thought out plan to transition to individualized services. We believe that consumers should enjoy individualized services which are portable and based on choice.

4. Quality Assurance Plan: The Center for Medicaid and Medicare Services review in 2000 indicated that there are health and safety issues that need to be addressed in communities across the State. MAIDS will continue to enthusiastically participate in measures that will help increase the health and safety of our consumers.

STAKEHOLDERS PRIORITY SHARING OPPORTUNITY
DECEMBER 12, 2001
PARENTS, LET'S UNITE FOR KIDS

In the last year, Parents, Let's Unite for Kids (PLUK) has made significant strides with respect to improving the organization of the agency and the public's awareness of the services provided. Many of the changes and improvements have been "behind the scenes" and will not be apparent to those outside of the agency.

All in all, PLUK has continued to focus on the mission of the program and providing services to families and children. In recent months we've added eight new members to the staff, five of whom working directly with families. This has been done in an effort to better serve families and to better cover the entire state of Montana.

We're involving volunteers much more than has ever been done, and we plan to grow that component even more. Our goal is to have 200 active volunteers by June of 2002. We've started Associate boards across the state and these groups of volunteers are meeting regularly. So far we have seven such Boards and our goal is to have ten by June of 2002. We're focusing on training more than in the past. This is actually the primary purpose of the organization, both with respect to our mission and with respect to the Department of Education grant that we receive. In January we implemented the monthly training series over an interactive TV system in the state. This has been successful and we have plans to enlarge this component as well. The success with that component has been with PLUK's ability to provide quality training to parents in some of the most rural areas of the state, consistently and monthly (not just a one time shot.) We're continuing to do what PLUK has always done and are exploring areas of need based on the feedback that we receive from parents.

PLUK's priorities for 2002 focus on making certain that we are available for and serve all families in Montana who need help. By adding staff we're already working toward that end. Another priority is to upgrading the number and quality of the training sessions that are done. Concerns include the lack of legal consultation available to families, confusion that is often present in the system, and a lack of collaboration within the system (note: we quickly acknowledge that many groups work closely together, but believe that even greater collaboration and an even deeper look at needs can be accomplished.)

People First of Montana
Comments to Developmental Disabilities Stakeholders
December 12, 2001

Good Afternoon everyone. My name is Jason Billehus and I am the President of Montana People First. I'd like to thank DDPAC for hosting this video conference. This afternoon, I'd like to tell the DD stakeholders more about the disability supports and services People First members need and want.

People First of Montana "works for services and supports that advocate for people with disabilities, that are helpful, timely, flexible, that empower people with disabilities, are not confusing, and help people with disabilities move out of poverty." This is part of our purpose statement from our Constitution and my comments today are based on our purpose.

When we talk about the supports people with disabilities need to live in the community, we are talking about ourselves, not some group of strangers we will never meet. When we look across the table at our meetings, we see friends who will need the supports I'll describe today. We want what is best for us and our members. At our meeting last August, members outlined the supports and services they felt were necessary to succeeding in the community.

Choice of services is important. We need to have a choice in where we live. We need places that are affordable and accessible and belong to us. We also need choice in what supports/services we want and who will provide our supports and services.

Some of us need assistance in our own homes. We might need help with personal care, help taking our medicines, or help with housework and shopping.

We want to learn more so we can be independent, but we need help learning. Tutors to help with reading and writing and to help us learn more math skills would be good.

Some of our members need help with our finances. We would like supports for budgeting, paying our bills so we can learn to be our own payees, and help keeping track of our money.

Communication is important, and communication assistance makes a big difference in our lives. Some people need help reading our mail and important papers. Others may need interpreters or assistive communication devices.

Everyone needs good quality health care. We would like to have health insurance, especially when we work. We need to see good doctors, dentists, and public health nurses if necessary. Sometimes we need help with medications. To stay healthy we need help with nutrition and grocery buying, if we ask for this help. And everyone needs education about sexual health and sexuality.

Transportation is a huge problem for people with disabilities. We need accessible, affordable, timely transportation, so when we need to go somewhere, we can go. Most of our members live in poverty. We need financial assistance just to get through the month. Some things that help us are Section 8 Housing assistance, Food stamps, and Social Security benefits, but we need help understanding these services. What makes the biggest difference for us are jobs with real wages in the community.

People First members are citizens, but we may need help advocating for our rights. Many of us need help with Social Security or help if we're discriminated against. We need to make sure our Civil Rights are respected. We are working on making the community accessible and we want to educate the police and others about disability.

We want what is best for us and our members. The supports and services I've talked about today are what our members have said are the most important. When you are designing services for us, or deciding what services to fund, please keep in mind what we have suggested today. Good services make the difference in the quality of our lives.



COMMUNITY SUPPORTS & SERVICES

Mission Statement

People First of Montana
“works for services and
supports that advocate for
people with disabilities, that
are helpful, timely, flexible,
that empower people with
disabilities, are not confusing,
and help people with
disabilities move out of
poverty.”



COMMUNITY SUPPORTS & SERVICES

Choice

- about where we live, places that are affordable and accessible and mine;
- of what supports/services we want;
- in who will provide our supports and services.



COMMUNITY SUPPORTS & SERVICES

Assistance in our own homes:

-with personal care;

-medicines;

-housework and shopping.



COMMUNITY SUPPORTS & SERVICES

Tutors

**-to help with reading and
writing;**

**-to help learn more math
skills.**



COMMUNITY SUPPORTS & SERVICES

Help with our finances

- budgeting;
- paying bills and learning to be our own payees;
- keeping track of our money.



COMMUNITY SUPPORTS & SERVICES

Communication Assistance:

- people to help us read our mail and important papers;
- interpreters (ASL, signed English, etc.);
- assistive communication devices.



COMMUNITY SUPPORTS & SERVICES

Health Care:

- health insurance, especially when we work;
- good doctors/dentists/public health nurses if necessary;
- help with medications;
- help with nutrition/grocery buying if we ask for this help;
- education about sexual health and sexuality.



COMMUNITY SUPPORTS & SERVICES

Transportation

-accessible;

-affordable;

**-timely: when we need it,
where we want/need to go.**



COMMUNITY SUPPORTS & SERVICES

Financial Assistance:

- Section 8 Housing assistance;**
- Food stamps;**
- Social Security benefits;**
- jobs with real wages in the community.**



COMMUNITY SUPPORTS & SERVICES

Advocacy and help with our rights:

- help with Social Security
- help if we're discriminated
against;
- help making sure our Civil Rights
are respected;
- help making the community
accessible;
- sensitivity training for police and
others about disability.

PARTNERS-IN-POLICYMAKING OF MONTANA, INC.
TRANSCRIPT OF PRESENTATION DECEMBER 12, 2001
JIM BEYER, PRESENTER

My name is Jim Beyer. I live here in Missoula and my wife Gwen and I have three children, 11, 9, and 7. My youngest child, Lauren was born blind. I am a local businessman and I am also the Chairman of Partners-in-Policymaking of Montana, Inc.

Partners-in-Policymaking of Montana is a registered Montana corporation and currently has a pending status as a 501 ©(3) non-profit corporation. We are an all-volunteer organization. We are currently funded through a generous grant through DDPAC, however, once our non-profit status is secured we will be seeking to augment that funding with other sources. We are very grateful to DDPAC for their kindness towards our program however, the vision that we have for our mission is greater than that grant alone can sustain.

Allow me to quote from our bylaws in order to inform you of our mission. "The purpose of Partners is to work together to unite advocates and persons with disabilities to promote education, and to advocate for change through the Legislature and state systems. Partners shall accomplish this mission by: (1)utilizing partner unity to represent our organization to build a network for building coalitions, communicating, cooperating, collaborating and establishing consensus on common goals; (2) raising public awareness of disability issues in order to promote integration and acceptance of and to improve advocacy for persons with disabilities; (3) affecting legislative processes by educating legislators, testifying, building agendas, providing input on legislative drafts or budget issues; (4) working to affect system change by serving on local, regional, state and national task forces and councils, and by creating a vision for the future of services, supports, policy and legislation that affect persons with disabilities and their families."

All current members of Partners have gone through a wonderful training program administered through DDPAC. The program lasted six months for each cadre trained. We are not holding a training event this year although we hope to have one soon.

We accomplish our purposes through three main areas of activity.

First, Partner's Legislative and administrative policy committee establishes an annual agenda regarding statutory, administrative rule and funding issues. We then mobilize our membership to affect our agenda by educating those with the influence needed to bring about needed change. We also communicate with legislators by appropriate means in order to allow our voice to be heard at critical times of decision. This includes testifying at hearings, faxes, e-mails, telephone conversations, and letters.

Secondly, Partners increase awareness of educators and the general public through a variety of venues. We do not overlap with the fine work that PLUK performs in the area of parent advocacy in individual IEP sessions, however. Our focus targets more at administrative and policy issues than individual ones. We may testify at school board

meetings or meet with school district staff regarding disability issues. We have presented workshops at the annual MEA convention. We also strongly support and labor for the March "Disability Awareness Month" program.

Finally, we serve on a variety of task forces and Councils where we often represent the viewpoint of consumers or parents. There are several partners on DDPAC itself as well as the Family Support Services Advisory Council, SPAM, and many others in our state as well as national and regional councils.

Thank you for the opportunity to present Partners to you all today. We look forward to working with all of you in the future in this most worthy field.

Swingley, Deborah

From: Christianson, Dain
Sent: December 13, 2001 9:10 AM
To: Swingley, Deborah
Cc: Fairclough, Julie; Martin, Novelene; Wethern, Connie
Subject: Written summary of comments

Following is a write up of the comments made by Dain Christianson during the Tele-Conference on 12/12/2001:

I appreciate the conciseness of Dave Eaton's statement of the service needs identified by MAIDS.

1. Statewide there is a need for more DDP field staff and Case Managers as the level of involvement for these positions has increased with the individualization of services (e.g. Community Supports). The numbers of people served have increased, the location of people served is more dispersed with Community Supports and more providers are becoming qualified to provide services. Future individualization of services with choice and portability will further increase the level of involvement needed to provide adequate quality assurance.

2. The loss of food stamps to group home residents is a serious problem for residents of these homes and the corporations that provide group home service. This is a loss of funds that cannot be covered by contract funds, the bulk of which are Title XIX and cannot be used for room and board expenses. Required cost allocation principles prevent utilizing title XX funds if they are even available. An example of the extent of this loss is taken from Milk River Inc. of Glasgow. The monthly food stamp allotment has decreased by an average of \$50 per person for each of the fourteen people served by Milk River's Group Homes. This is an annual loss of \$8,400 per year. The loss of LIEAP funds just adds to the problem. Milk River lost \$2,600 per year in LIEAP.

3. Legal reforms are needed to "accommodate" people with developmental and other mental disabilities. Persons with mental disabilities currently are not dealt with by the courts but "ordered" to DDP services. When the legal system does get involved with individuals with developmental disabilities the individual is often not afforded the legal protections available to the non-disabled population. "Forensic" services are needed to assist the legal system and provide services to individuals with developmental disabilities who are found guilty of a crime.

4. Respite has been a valuable part of the services provided to families of children with developmental disabilities and some adults who live with their families. The increased cost of providing respite resulting from wage and hour requirements will significantly reduce the amount of this valuable and in some cases essential service. Additional funding needs to be provided to cover the increased costs.

(I overlooked mentioning this fourth point at the Form Tele-conference and would like to submit it now.)

Priority Area Input - DD PAC Forum - 12/12/01
Submitted by STEP, Inc.

1. Support activities, which assist state and provider agency staff to assure consumer voice and participation in systems change.
2. (From Dan Barthuly) Educate consumers about systems change and what it means to them. Revamp tools that are currently available and utilize existing structures and resources to provide information in a number of different ways.
3. Support short term occasional respite changes which focus on consumer choice and flexibility. This may be done in a number of ways, specifically:
 - a. looking at legislative changes in the law which allows short term occasional respite to fall under domestic servant or companionship laws
 - b. Incorporating a state Lifespan Respite program into state respite changes to ensure the availability and affordability of quality respite to all families in need across human services.
4. Increase wages and quality of education for direct care staff and promote direct care as a vocational option. (This includes "respite care")

Swingley, Deborah

From: Rita Schilling [jcimt@imt.net]
Sent: December 13, 2001 4:24 PM
To: Deborah Swingley
Subject: written testimony

The provider network needs adequate funding to build infrastructure. This includes adequate staffing levels, pay commensurate with responsibilities, updating buildings, vehicles and technology.

People in services need ready access to transportation in order to work and to fully participate in community life.

Thanks, Rita Schilling

CONCLUSION AND ACKNOWLEDGEMENT

The gathering of all this information, although an arduous task at times, was the easy part. Now comes the hard part. . . . how can the Council, the Montana Advocacy Program and the Disability Services Division/Department of Public Health and Human Services implement, or try to implement responses to all these needs. Short of being "SUPER" human service agencies, we can't.

We do pledge that this information will be presented to policymakers who make decisions in resource allocation, to make the very best "investments" we can to improve the system, and to chart new service options in some instances.

The ability to ask for and receive input -- be it angry, happy, frustrated, satisfied or exasperated from the people involved in this system and the public assures that we will have a service delivery system that is responsive to the needs of persons receiving those services.

So to all of you who took the time to attend the public forum in your area, our sincere thanks;

To all of you who allowed us to use your facilities so we could hold a public forum in your town, made us coffee and great cookies, our sincere thanks;

To all of you who took the time to complete a written survey and return it to us, our sincere thanks;

To all of you who took the time to distribute the survey tools among other groups to be completed and returned, our sincere thanks;

To all of you who attended and presented during the METNET opportunity, and submitted written copies of your presentation, our sincere thanks;

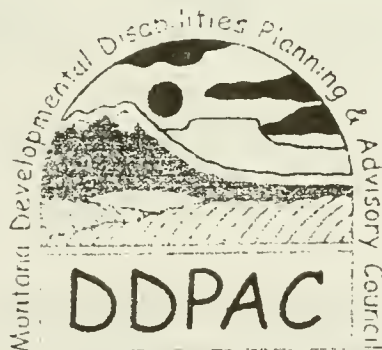
And, to all of you who said, "why are you asking me these questions again, I told you all this last time (or the time before or the time before that) and still nothing has been done", our sincere apologizes we'll keep trying.

Survey Time!

The Montana Developmental Disabilities Planning & Advisory Council realizes that families and individuals are bombarded with surveys from lots of different organizations and agencies. Although we try to limit the frequency of our surveys, there are times when we really need your information. *This is one of those times.*

The Council needs to know what you think are the most important issues facing individuals with developmental disabilities and their families. Gathering the opinions of people like you is an important and necessary step in determining the areas of emphasis that the Council will address in our State Plan. Your input in this survey will help assist the Council in determining the areas the Council will make funding decisions in the future. **We want to hear from you!**

This survey is also available in alternative formats. Please call us at 800/337-9942 (Montana Toll-Free) to make your request. We will do whatever we can to accommodate your needs.



**** NEEDS SURVEY****

Think of three issues that you believe will be the most important during the next five years for individuals with developmental disabilities and their families.

Review the following list. Circle those items that match your top three issues. If any of your priority issues are not listed, please add them under "Other."

- | | |
|--------------------------------------|--|
| Early Intervention | Feeling Safe in My Home |
| Special Education | Direct Support Professionals
(direct care workers) |
| Transportation | Information on Assistive Technology |
| Accessible and Affordable Housing | Employment Opportunities |
| Getting the Health Care I need | Respite Care that meets my needs |
| In-home Assistance | Directing my own support needs |
| Waiting List for Disability Services | Personal Assistant Services |
| Quality of Disability Services | Developing Leadership |
| Recreation Choices in My Community | Understanding Aging Services Available |
| Making and Keeping New Friends | Being Included in My Community |
| Feeling Safe in My Community | Understanding Financial Benefits (SSI/SSDI/etc) |
| | Helping People of Difference Cultures be More Comfortable in the Community |

Other: _____

Tell us a little about each of your priority issues.

First issue and what you want to happen:

Second issue and what you want to happen:

Third issue and what you want to happen:

Please feel free to list other issues and what you want to happen?

Please check all that apply:

- I have a developmental disability
- I have a family member with a developmental disability
- I work in the field of developmental disabilities

Circle the term that best describes you: (optional)

White	Hispanic
African American	Asian
Native American	Pacific Islander

Name: _____(optional)

Address: _____

City, State, Zip _____

Thanks for sharing your opinions with us. We hope to get as many surveys back by December 15, but we will gladly accept them anytime.

To Return: Fold in half, secure with tape or staple and mail.



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